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Current Therapeutic Management of Perinatal Stroke with a Focus on the Upper Limb: A Cross-Sectional Survey of UK Physiotherapists and Occupational Therapists

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ABSTRACT



Aim: To determine current UK pediatric physiotherapist (PT) and occupational therapist (OT) management of perinatal stroke. **Design:** Web-based cross-sectional survey. **Methods:** Participants were members of the Association of Paediatric Chartered Physiotherapists and Occupational Therapists specialist section: children young people and families working with infants. Items covered prioritization of referrals, assessments, therapy approaches aimed at the upper limb, and parental support. **Results:** 179 therapists responded. 87.2% of PTs and 63.0% of OTs managed infants with perinatal stroke. Infants with clinical signs of motor dysfunction at referral were prioritized for early initial assessment. The most frequently used assessments were the Alberta Infant Motor Scale (AIMS) and Bayley Scales of Infant Development (BSID). Of PTs and OTs, 41.9 and 40.0% used no standardized assessments. Frequently used therapy interventions were Bobath/Neurodevelopmental Therapy (NDT), positioning aids and passive movements. 88.1% of therapists would choose a bilateral rather than unilateral (affected side) therapy approach for infants with perinatal stroke aged up to 6 months. Of PTs and OTs, 56.9 and 57.1% provided psychological support to families. **Conclusions:** Assessment and provision of therapy services following perinatal stroke is variable. Increased use of standardized assessments and centralized data collection regarding service provision for high-risk infants is recommended.

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Introduction

Perinatal stroke is a cerebrovascular event occurring during fetal or neonatal life, before the 28th day after birth (Raju, Nelson, Ferriero, & Lynch, 2007), and is the leading cause of unilateral cerebral palsy (UCP). Stroke risk in the first week after birth is higher than any other week throughout life (1/2300 term and 7/1000 preterm deliveries) (Kirton, 2013). Due to upper limb weakness, spasticity and/or dystonia, children with UCP often struggle with activities of daily living requiring skilled bimanual function, with consequences for self-esteem, peer relationships, and employment (Beecham, O'Neill, & Goodmanodman, 2001; Goodman, 1997; Russo et al., 2008; Skold, Josephsson, & Eliasson, 2004). Other aspects of motor function including gait are often affected; comorbidities include seizures, behavioral and cognitive difficulties (Neville & Goodman, 2000).

A diagnosis of UCP following perinatal stroke occurs months to years after the initial cerebrovascular event. This is partly due to the nonspecific nature of early clinical features, such as seizures and subtle encephalopathy, mild global movement abnormalities, and developmental delay in the early months of life. Furthermore, lateralized motor difficulties emerge gradually over time after perinatal stroke (Chen, Lo, & Heathcock, 2013; Chen, Tafone, Lo, & Heathcock, 2015). Delays in recognition of emerging motor problems, late referral to appropriate services, and clinical uncertainty regarding outcome in the context of post-lesional neuroplasticity, also contribute to late diagnosis of UCP.

Animal studies indicate that early lateralized intervention while corticospinal tract and spinal cord circuitry are still developing may substantially improve outcome (Martin, Chakrabarty, & Friel, 2011). No consensus exists regarding intervention for the upper limb in infants prior to the diagnosis of CP, though many options exist for children with established UCP. There is ongoing research into early modified constraint-induced movement therapy (CIMT) (Nordstrand, Holmefur, Kits, & Eliasson, 2015), action-observation (Burzi, Tealdi, Boyd, & Guzzetta, 2016; Guzzetta et al., 2013), and early lateralized intervention (Basu, Pearse, Baggaley, Watson, & Rapley, 2017).

Prior to trialing therapeutic rehabilitation interventions for the early months after perinatal stroke, we need to understand current practice. Our survey aimed to investigate current management of perinatal stroke by UK physiotherapists (PTs) and occupational therapists (OTs). Our objectives were to obtain descriptive data regarding early identification, early therapy interventions for the upper limb, and therapist support for parents. By documenting current National Health Service therapist management of perinatal stroke, we can describe how proposed therapeutic interventions will differ from current management.

Methods

Study design, recruitment, and participants

We undertook a web-based cross-sectional survey of management of perinatal stroke by UK-based neonatal and pediatric PTs and OTs. PTs were approached through the Association of Paediatric Chartered Physiotherapists (APCP) and OTs through the College of Occupational Therapists Specialist Section: Children, Young People, and Families (COTSS-CYPF). An e-mail invitation including a URL for the online survey was distributed via group mailing lists, requesting responses only from therapists

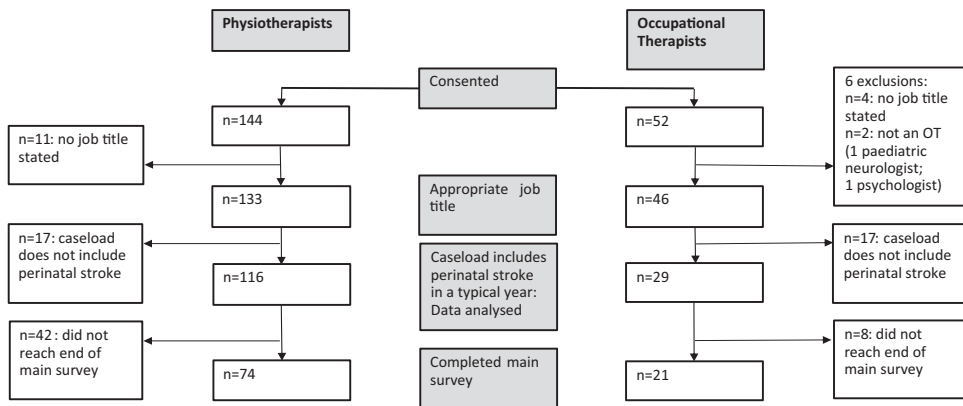


Figure 1. Participant flow diagram.

working with infants. Paper copies were available on request. A screening question determined whether the therapist's caseload typically included infants with perinatal stroke.

Figure 1 details participant flow. One hundred and seventy-nine participants had therapist job titles indicating eligibility to complete the survey. One hundred and thirty-three (74.3%) were pediatric PTs, of whom 10 specialized as neonatal PTs, 46 (25.7%) were pediatric OTs, of whom one was a neonatal specialist. Neither the APCP nor the COTSS-CYPF had information on the number of UK therapists managing infants with perinatal stroke, so we could not ascertain response rates or bias.

Of the 179 eligible respondents, 87.2% ($n = 116$) of PTs and 63.0% ($n = 29$) of OTs reported having infants with perinatal stroke in their caseload in a typical year. These 145 questionnaires were further analyzed. Of these 145 respondents, 62.1% of PTs and 58.6% of OTs worked in community settings; 18.1% of PTs and 24.1% of OTs worked in acute hospital environments; 19.8% of PTs and 13.8% of OTs worked in both acute and community settings. One OT worked for a charity.

Seventy-four PTs and 21 OTs continued to the end of the survey as indicated in Figure 1. It was possible for respondents to continue through the survey without providing an answer to every item: most survey questions were completed by 74 PTs and 21 OTs, with a few minor exceptions. Missing responses are listed in Supplementary Table S1.

Questionnaire design and administration

A review of early intervention in perinatal stroke was completed prior to survey design and administration (Basu, 2014). The survey content was dictated by the need to understand current practice in therapist management of infants with perinatal stroke in UK, to inform the design of a trial of an early therapy intervention for the upper limb (Basu et al., 2017). The concept of current practice was subdivided into dimensions of interest, relating to the timing and prioritization of referrals; commonly used early assessments of motor function; early therapy intervention; frequency of follow-up; and support for parents.

Table 1. Summary of Survey Topics

Topic	Content within topic
General/demographic	Job title and practice setting
Screening question	Caseload includes infants with perinatal stroke
Early identification	Age at referral; Prioritization; Assessment of motor function
Early intervention	Therapy approaches; Follow-up
Support for parents	Provision of written materials; Psychological support

The questionnaire was prepared following guidance from National Centre for Social Research training course materials on questionnaire design. To develop questions with face validity, a multidisciplinary core group was set up comprising two PTs (both working in the neonatal unit; one also covering acute pediatrics); a senior pediatric OT with acute, neonatal and community experience; a biomedical sciences student with epidemiology research experience; a statistician; a consultant neonatologist; and a pediatric neurologist with a research interest in perinatal stroke. All group members reviewed all survey items at least once; opinions were also sought from other students, trainees, and therapists. Critical review and piloting by local neonatologists and therapists were undertaken to assess content, comprehensibility, and acceptability; and to identify and remove potential sources of response bias. Feedback from these processes led to multiple improvements in the survey content (e.g. inclusion of definitions and standard use of terminology throughout; inclusion of free text boxes where appropriate; identifying essential aspects of content; and removal of unnecessary items) as well as the clarity of question wording and the order and flow of the survey. Once the survey content had been finalized, it was transferred to SurveyMonkey® for ease of administration and tested a further ten times by AT and APB to ensure the setup, skip logic, consent, and data representation processes were correct.

Table 1 summarizes topics covered in the final questionnaire. There were 25 items plus an opportunity to provide general comments at the end. At the start of the questionnaire, perinatal stroke was defined for participants as “a cerebrovascular event occurring during fetal or neonatal life, before the 28th day after birth” (Raju et al., 2007). We stated that we were interested in both ischemic and hemorrhagic strokes. Skip logic was used twice; to allow participants without infants with perinatal stroke in their caseload to exit the questionnaire, and to allow participants who did not provide written materials to skip the question about the nature of such materials. Most questions offered fixed-choice responses (i.e. were multiple choice questions), though there were some opportunities to input free text. For most questions, only one response could be selected, but for the questions regarding assessments and therapy approaches used, participants could select all applicable responses. Item presentation order was fixed but participants could review and alter their responses. The survey was open for 4 weeks between July and August 2015, with a reminder at 2 weeks.

For the item on infant age at referral, we provided eight age ranges (spanning referral prior to term equivalent age, up to referral aged over 18 months), to be ranked by frequency. For items regarding prioritization of referrals, we asked: “Would infants with perinatal stroke be classed as High/Medium/Low priority: (1) if there were clinical signs of motor dysfunction at referral and (2) if there were no clinical signs of motor dysfunction at referral.” Participants could choose one response only but could opt to choose “variable” and add a free text response. Participants were also asked

which factors other than motor dysfunction would increase the urgency for initial assessment.

Participants were asked which assessments they used, choosing all that applied from the following list of measures: “No specific named neurological assessments; Alberta Infant Motor Scale (AIMS); Pediatric Stroke Outcome Measure (PSOM); General Movements Assessments (GM); Bayley Scales of Infant Development (BSID)”; and Other (which they were asked to list as free text). The AIMS is a validated, quick assessment of motor performance in the first 18 months of life (Darrah, Piper, & Watt, 1998). The PSOM (Kitchen et al., 2012) is the only disease-specific measure of neurological outcome after pediatric stroke and has a scale for use from birth to 2 years of age. GM assessments provide a Gestalt classification of the quality of spontaneous infant movements, and have a high sensitivity and specificity for the prediction of cerebral palsy in high risk infants (Bosanquet, Copeland, Ware, & Boyd, 2013). The BSID (Bayley, 2006) is frequently used in infant neurodevelopmental follow up from 1 month to 42 months of age.

Participants were asked what therapeutic approaches they used for upper limb motor dysfunction, choosing as many responses from the following list: Bobath/Neurodevelopmental Treatment (NDT), bimanual, modified CIMT, passive movements, Sensory Integration Therapy, splinting, functional taping, and positioning aids. This was done separately for age groups 0–6 months, 6–12 months, and 12–24 months. Therapists could also list any other therapy approaches used. Our list was chosen based on the literature (Novak et al., 2013), our interest in early therapy approaches for the upper limb, and our experience of UK practice. We included NDT because our perception was that this remains widely used by UK pediatric therapists despite evidence of lack of benefit: we included sensory integration therapy and passive stretching for similar reasons (Novak et al., 2013). We included functional taping, as our perception was that it is increasingly used in this context, as is splinting; evidence for these approaches remains weak (Basu, Pearce, Kelly, Wisher, & Kisler, 2015; Novak et al., 2013). We also wanted to capture information on the use of bimanual and modified constraint-induced movement therapy, for which there is strong evidence of benefit in children and ongoing investigation of effectiveness in infants (Boyd et al., 2017). Positioning aids were included because correct positioning can facilitate hand function (Stavness, 2006). A free text box was available for further comments. We asked therapists whether they would concentrate on promotion of unilateral (affected side) or bilateral tasks for infants with perinatal stroke in the first 6 months of life. During this time frame, marked activity dependent corticospinal tract reorganization occurs (Eyre, Taylor, Villagra, Smith, & Miller, 2001). Early lateralized intervention has the potential to influence this process to improve motor outcome long-term (Basu et al., 2017).

Ethical approval

The study was approved by the Faculty of Medical Science Ethics Committee, Newcastle University. To ensure full compliance with the Data Protection Act (1998), online survey responses were anonymized by SSL encryption and disabling IP address tracking.

Participants were requested not to include personal information. Review of the information sheet and provision of a consent statement were required prior to participation.

Data analysis

Results were downloaded from SurveyMonkey[®] in .xls format. We examined the workplace settings of respondents who confirmed their job title as pediatric or neonatal PT or OT. Analysis of responses related to the management of perinatal stroke was restricted to participants who indicated in the screening question that they typically had such infants in their caseload. All questionnaires from eligible respondents were analyzed, even if incomplete: data on missing responses was tabulated. Analysis was descriptive: summary statistics were generated in Microsoft Excel 2013 (Microsoft Corporation, Redmond, WA). Free text responses were categorized by C.M. (and verified by A.B.) into groups representing similar issues. For analysis of age at referral, the number of responses in each rank for each age range was multiplied by the rank weighting (with “most often” receiving a rank of 8 and “least often” a rank of 1) and then expressed as a percentage of the total weighted scores. We compared, using chi-squared tests, the proportion of acute hospital versus community/mixed setting therapists using each therapeutic approach for upper limb motor dysfunction in the first 6 months.

Results

Early identification

Figure 2 shows the results of analysis of age at referral. Referrals from PTs predominated in the first 6 months of life and then gradually declined in frequency. Referrals from OTs were more evenly spread across the age categories.

Infants with clinical signs of motor dysfunction at referral were classed as high priority for initial assessment by 87.8% of PTs and 81.0% of OTs, in contrast to infants with no such signs identified—classed as high priority by 40.3% of PTs and 28.6% of OTs (Figure 3). These quotes from community pediatric PTs highlight the variability in service provision for infants with no motor signs at referral:

If there were absolutely no clinical signs of motor dysfunction, as defined by someone... who is qualified in looking for signs of motor dysfunction, I don't think I would be seeing them at all.

They would be high priority for assessment, but low priority for treatment if there were no signs of motor dysfunction.

Figure 4(A) demonstrates the combined results from PTs and OTs for the waiting time for initial assessment. Interestingly, 65.8% of PTs aimed to review infants within 4 weeks even where no motor signs were identified by the referrer, and 81.0% would aim for this time scale if motor signs were already identified. Sixty-two PTs and 19 OTs entered free text responses to the question regarding factors other than motor dysfunction which would increase the urgency of the initial assessment. Family anxiety and/or social concerns were mentioned by 34 respondents. Other factors were difficulties with

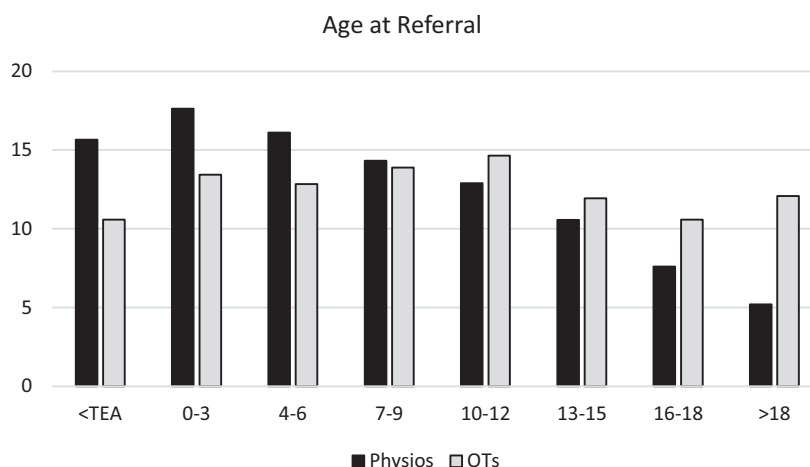


Figure 2. Age at referral to therapy services. Responses to question “At what (corrected) age are infants with perinatal stroke most often referred? Please rank the choices”. TEA: term equivalent age. Vertical axis: indication of frequency, expressed as percentage of total weighted scores. Black bars: responses from physiotherapists; gray bars: responses from occupational therapists.

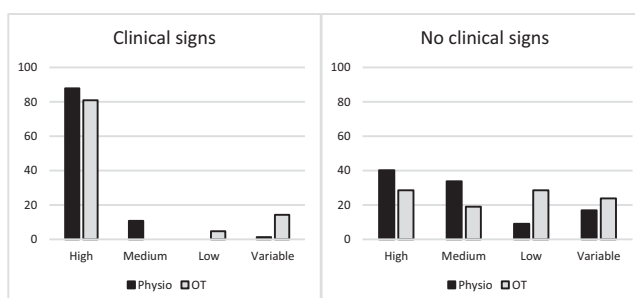


Figure 3. Prioritization of referrals. Responses to the questions “Would infants with perinatal stroke be classed as High/Medium/Low priority: (A) if there were clinical signs of motor dysfunction at the time of referral and (B) if there were no clinical signs of motor dysfunction at the time of referral”. Horizontal axis: prioritization category. Vertical axis: percentage of respondents.

posture and positioning, respiratory and feeding complications, and the presence of other medical conditions.

36.5% of PTs and 23.8% of OTs felt confident in identifying movement difficulties in infants aged 3 months; 62.2% of PTs and 61.9% of OTs were confident by age 4–6 months. Of PTs and OTs, 40.0 and 41.9% used no standardized assessments. The two most-used assessments were the AIMS: 52.7 and 35.0% of PTs and OTs; and BSID: 44.6% of PTs and 40.0% of OTs. GM assessments were used by 20.3% of PTs and 15.0% of OTs. Regarding additional assessments volunteered by over 5% of respondents, PTs also used the Hammersmith Infant Neurologic Examination (HINE) (8.1%) and Lacey Assessment of Preterm Infants (LAPI) (8.1%). 25% of OTs also used the Peabody Developmental Motor Scales. Other assessments including the Gross Motor Function Measure, Test of Infant Motor Performance, Movement ABC were each volunteered by <5% of respondents. The Pediatric Stroke Outcome measure was also used by <5% of

respondents. Only one therapist (an OT) indicated use of the Assisting Hand Assessment (AHA) in the free text box. The use of assessments was similar between PTs working in acute hospital settings only and those in community or mixed settings, except for the AIMS (80% of “acute” PTs; 48.8% of “community/mixed setting” PTs). Given the smaller number of OT respondents, we did not similarly split their responses between those from acute versus community/mixed settings.

Early intervention and follow-up

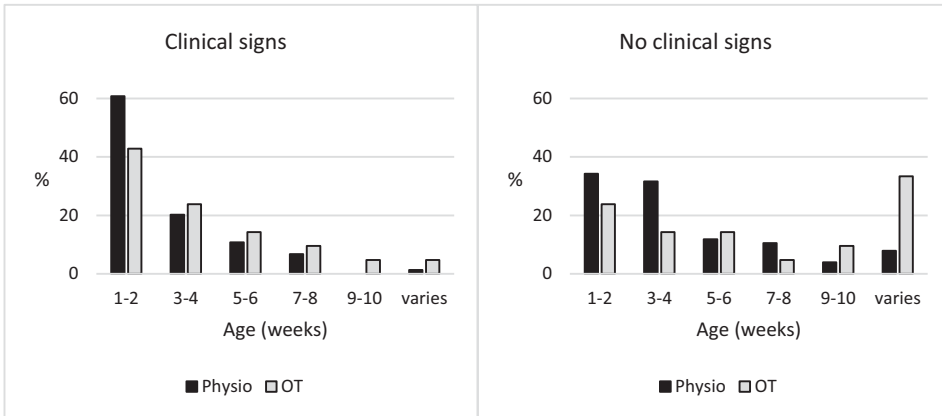
Figure 4(B) summarizes the frequency of follow-up appointments for infants with perinatal stroke: 28.4% of PT and 28.6% of OT respondents would review infants with clinical signs of motor impairment at least weekly; a further 33.8% of PTs would review fortnightly. Therapists provided free text information indicating how the social, clinical (e.g. severity and rate of change of clinical features with time), and family (parental understanding and confidence) context would influence their follow-up plans. Infants with no clinical signs of motor impairment were most likely to be reviewed monthly by PTs (44.2%) and on demand by OTs (38.1%), with six responses suggesting no follow-up would be provided, and six indicating that parents would be given contact details and advised to get in touch as required. Free text responses also indicated that the duration of follow-up would depend on individual circumstances such as achievement of specific milestones e.g. walking.

Figure 5 summarizes the data on interventions used for the upper limb in infants with perinatal stroke. Bobath/NDT and positioning aids were the most frequently used approaches by PTs and OTs, alike, though by 12–24 months OTs were also frequently using bimanual therapy and modified CIMT. Hydrotherapy and “targeting functional activity” were listed in free text comments. There were no significant differences in the proportion of acute hospital versus community/mixed setting PTs using each approach in the first 6 months. We did not repeat the analysis for OTs, due to the smaller number of OT respondents. A high percentage of therapists, 87.9% (58/66) of PTs and 88.9% (16/18) of OTs, chose a bilateral rather than unilateral task approach.

Parental support

Many therapists, 67.6% (50/74) of PTs and 66.7% (14/21) of OTs, provided written materials to parents to support intervention delivery. These included individualized developmental play plans: “Physio tools” (an online library of physiotherapy exercises: <http://www.physiotools.com/>) and other information such as advice regarding local facilities and baby groups. Slightly more than half of the therapists, 56.9% (41/72) of PTs and 57.1% (12/21) of OTs, provided psychological support to parents. Therapists, through their free text responses, highlighted the informal nature of the psychological support they offered. Several therapists said they had a counseling role or provided emotional support. Support included signposting to other services, and offering introductions to other families with an infant with perinatal stroke. Six respondents had a psychologist available to the team.

4A: Initial Assessment



4B: Follow up

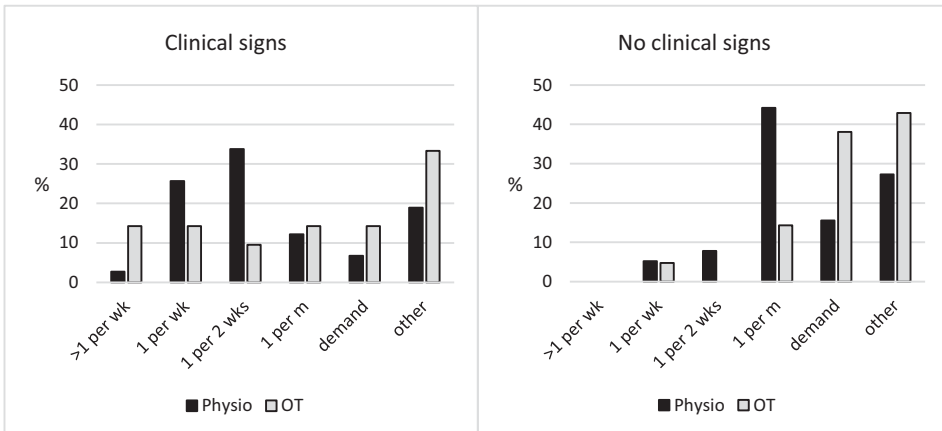


Figure 4. (A) Left: Responses to the question “Within how many weeks do you typically see an infant with perinatal stroke whom you have been advised has clinical signs of motor dysfunction in order to carry out an initial assessment?” Right: Responses to the same question but for infants in whom no clinical signs of motor dysfunction were identified by the referrer. (B) Left: Responses to the question “How frequently would you expect to follow up an infant who has suffered a perinatal stroke and who currently has clinical signs of motor dysfunction?” Right: Response to the same question for an infant who currently has no clinical signs of motor dysfunction.

Discussion

Summary and principal findings

This study used an online survey to investigate UK PT and OT management of perinatal stroke. Most respondents worked in the community (i.e. seeing patients in a local clinic or in their homes) and were PTs. Our survey demonstrates variability both in assessment and subsequent management.

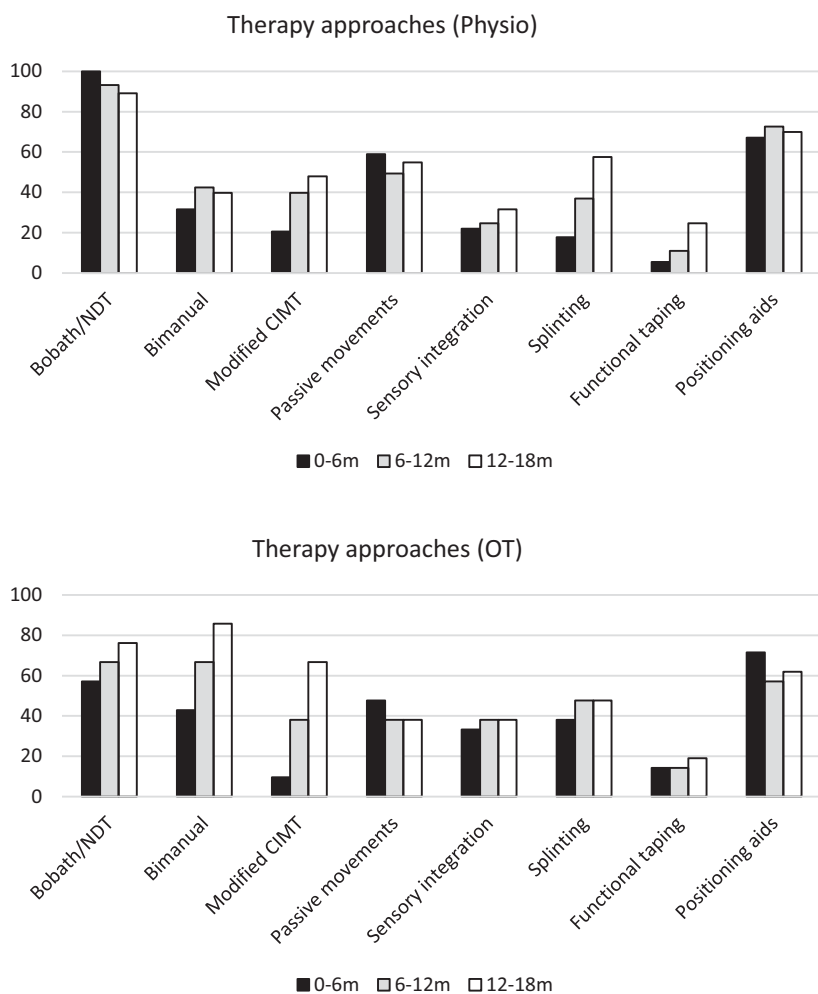


Figure 5. Response to the question “What therapy approaches do you use for infants with perinatal stroke at different ages, in order to address upper limb motor dysfunction? Please tick all that apply”. All options provided in the dropdown list are shown. Top: Physiotherapists. Bottom: Occupational therapists.

Early identification

Neurological deficits occur in up to 60% of infants following perinatal stroke, with UCP occurring frequently (Sreenan, Bhargava, & Robertson, 2000). Signs of hemiplegia are often initially absent, emerging gradually in the first year of life. Examination using GM assessments detects early abnormalities in the complexity, fluency and variability of movements and by around three months, subtle asymmetries may be seen (Guzzetta et al., 2003; Guzzetta et al., 2009). Neuroimaging also has predictive value for motor outcome after perinatal stroke (Husson et al., 2010): in practice, clinicians use information from MRI brain imaging, clinical review, and assessments such as GMs in combination to evaluate the risk of cerebral palsy. For those infants diagnosed in the neonatal period with stroke with a high risk of developing UCP based on assessments such as

GMs and MRI brain, early referral to therapy services is indicated. Similarly, for infants with perinatal stroke who were not diagnosed in the neonatal period, early identification of emerging hemiplegia is vital to facilitate early referral to therapy services.

Responses indicated that around one-third and one-half of infants were referred to physiotherapy and occupational services respectively beyond the age of 9 months. Delays between the onset of parental concern and diagnosis have been reported (Kirton, Deveber, Pontigon, Macgregor, & Shroff, 2008). As well as delaying intervention, delays in diagnosis and referral to early intervention services have implications for parent--child interaction and parental psychological well-being (Baird, McConachie, & Scrutton, 2000).

It is also important to be aware of the natural history of perinatal stroke, to avoid discharging neonates at high risk of morbidity from follow-up too early, as signs of hemiplegia may emerge subsequently. Reassuringly, around two-third of PTs in our study aimed to review infants within 1 month even where no motor signs were identified by the referrer.

Most therapists felt confident in identifying movement difficulties in infants with perinatal stroke by 4–6 months of age. This is similar to the average age at presentation of infants with presumed perinatal stroke (5 months) (Kirton et al., 2008). The use of formal assessments in such infants was variable. Despite the predictive value of GM assessments in high-risk infants (Bosanquet et al., 2013; De Bock et al., 2017), these were used by only 20.3% of PTs and 15.0% of OTs surveyed. GM assessment requires specific training and frequent practice to maintain skills. The AIMS was frequently used and this is entirely appropriate for identifying motor delays in infants aged ≤ 18 months; however, once abnormal movement patterns are identified, the AIMS should not be used to evaluate motor development over time (Piper & Darrah, 1994). Over 40% of therapists did not use any form of standardized assessment to monitor infant progress.

Our survey indicates a need for specialist neonatal and early years therapists to be equipped to assess and follow up high-risk infants using standardized assessments, providing high quality, objective, and reproducible summaries of outcome (Harniess & Nikopoulou-Smyrni, 2015; Spittle, Doyle, & Boyd, 2008). This is in line with the 2009 Department of Health toolkit for high quality neonatal services (NHS & Department of Health, 2009) and the 2017 NICE guidelines for cerebral palsy (National Institute for Health & Care Excellence, 2017). Components of the neonatal PT competency framework produced by the APCP (Brady & Smith, 2012), particularly those related to infant examination and evaluation, would also benefit community physiotherapists working with young infants. The framework for these components sets out the recommended clinical proficiencies and knowledge areas, including appropriate developmental assessments.

A recent systematic review summarized the data on the predictive value for cerebral palsy of early assessment tools (Novak et al., 2017). For evaluating hand function in UCP, the AHA from 18 months of age, mini-Assisting Hand Assessment (mini-AHA) ages 8 to 18 months, and now also the Hand Assessment for Infants (HAI) ages 3 to 12 months form a valuable suite of assessments with Rasch-based scores. The HAI differs from the other two assessments in providing information on the function of each

hand separately as well as bimanual function. Training on administration and scoring of these assessments is required. Simultaneously, there is a need for prompt referral to therapy services: this requires widespread training of clinicians with infants on their caseloads, to recognize early signs of motor difficulties. At present there is a “catch-22” in some referral criteria: high-risk infants are prioritized for review if they have abnormal motor signs; however, not all practitioners are trained to identify these signs using approaches such as GM Assessments.

Early intervention

All of the PT respondents stated that they would use the Bobath/NDT approach between 0 and 6 months; most would continue to use this, alongside other treatment modalities, until 2 years of age. As the ingredients of the Bobath/NDT approach vary and are often not specified it is hard to evaluate as a single entity. It is interesting that, despite the lack of a definition of NDT, conflicting evidence of benefit from systematic reviews, and given the evidence that motor learning approaches provide superior outcomes in CP (Novak et al., 2013), UK therapists still strongly identified themselves as users of this approach. Similarly, while sensory integration therapy was used by a minority of respondents, there is evidence that this approach is ineffective (Vargas & Camilli, 1999). In future surveys, it would be valuable to itemize key intervention ingredients for selection by respondents, to avoid the ambiguity around the meaning of NDT. Passive movements and use of positioning aids were also popular treatment modalities; however, we did not have information on the context in which these interventions were applied. A positioning aid may be used to support achievement of a variety of treatment goals, and may be considered as a form of environmental modification. Environmental modifications, child-initiated movements, and task-specific training are all promising approaches (Morgan et al., 2016). However, a review of the efficacy of passive stretching in children with CP was inconclusive due to disparate findings from several small studies and a lack of high quality trials (Pin, Dyke, & Chan, 2006). Splinting was a frequently chosen intervention for older infants, though the evidence base remains weak (Novak et al., 2013).

Most therapists preferred a bilateral task approach over a unilateral (affected side) approach for infants with perinatal stroke in the first 6 months of life. While this is understandable in terms of gross motor development goals, consideration must be given to the potential for activity-dependent corticospinal tract reorganization to influence outcomes in terms of upper limb function. Promoting activity of the potentially affected upper limb after perinatal stroke could influence this reorganization (Eyre et al., 2001). Caution is needed if considering CIMT in infancy, to avoid detriment to the development of motor control of the less-affected side (Basu & Eyre, 2012); though no such detriment has been noted with judicious use of “baby-CIMT” (Nordstrand et al., 2015). The evidence base for interventions in infants at high risk of unilateral CP is still growing; our group is evaluating one such approach (Basu et al., 2017). Currently therefore, the choice of therapy approach remains empirical.

Parental support

Stress and anxiety levels are high for parents of high-risk infants (Baird et al., 2000). The effect of a disclosure of risk or diagnosis of neurological impairment can influence a parent's capacity to develop coping mechanisms. Feelings of guilt and blame are common (Bemister, Brooks, Dyck, & Kirton, 2014). Over half of our survey respondents reported supporting parents psychologically. Further consideration is needed to identify how therapists and other healthcare professionals can best support parents, delivering interventions that will promote their child's development, family functioning, and quality of life. While increased provision of formal psychology input for families is one potential solution, provision of training for therapists around the psychological needs of families of infants with conditions such as UCP and how to support them could also be valuable.

Strengths and limitations

Strengths of the study include the multidisciplinary research team, piloting of the survey, relative brevity of the survey (taking around 5 min to complete), and opportunities for free text responses. Limitations include inability to ascertain response rates due to a lack of UK data regarding therapists with infants in their caseload, and the absence of financial incentives to participate, which may have affected survey completion. While 145 participants completed initial items, only two-thirds completed the survey, introducing potential nonresponse bias. Furthermore, other demands on individual therapist time and resources, including overall caseload, were not explored.

We explored the issue of response rates in some detail. The UK membership of APCP is around 2200; membership of COTSS-CYPF is over 700. The proportion of these practitioners working with high-risk infants is probably small: in our Hospital Trust, less than one-sixth of pediatric PTs (including community therapists) have regular contact with such infants in a neurodevelopmental context. While the APCP has a neonatal special interest group and the COTSS-CYPF has a clinical forum on early intervention, membership numbers for these groups are not available. More detailed data would facilitate workforce planning and resource allocation as well as training and subspecialty accreditation.

Our screening question specifically related to whether therapists had infants with perinatal stroke on their caseload in a typical year. While not formally stated, the typical UK medical definition of an infant would relate to the first year of life. It is unlikely, but possible, that the lack of a formal understanding of the word infant in this context caused some therapists to exit the survey early. Subsequent questions requested a breakdown of information by age, e.g. age at referral; therapy approaches used in particular age groups covering the first 2 years of life (to allow for likely length of follow up in a trial), thus avoiding ambiguity regarding the age range of interest. Perinatal arterial ischemic stroke affects up to 1/2300 term-born infants (Schulzke, Weber, Luetsch, & Fahrenstich, 2005), and there were 777 165 births in UK in 2015 (Office of National Statistics; National Records of Scotland; Northern Ireland Statistics and Research Agency), so we would expect fewer than 340 new cases per year. Therapists would be expected to cluster their expertise in managing high risk infants, and there are 205 UK

neonatal units, so our response rate of 116 PTs UK-wide who passed the screening question seems acceptable for a survey of professional groups (de Vaus, 2002). A survey sent through the same mechanism in 2015, targeting UK-based lead pediatric PTs for early years follow-up, had a response from 97 PT, only 57 of whom were involved in the follow-up program (Harniess & Nikopoulou-Smyrni, 2015). We suspect the number of UK OTs with a neonatal/high-risk infant caseload is small. Despite the 2009 Neonatal toolkit recommendations, neonatal OTs remain scarce.

As with any survey, bias may be introduced: some responders may second-guess “preferred” responses. Thus, the survey may suggest a higher standard of care than that provided in practice. While we cannot demonstrate conclusively that the data are representative of UK-based therapists, the observed variability in prioritization of infants, assessment and intervention approaches, and resources for parental support matches our clinical experience. The importance of early assessment and intervention is increasingly recognized: recent NICE guidance on developmental follow-up of those born pre-term (Kallioinen, Eadon, Murphy, Baird, & Committee, 2017) and the review of early diagnosis and intervention in cerebral palsy (Novak et al., 2017) will impact positively on this field. It is likely that repeating this survey in future will demonstrate marked changes in practice. With a repeat survey, further data on the experience and training of respondents would be interesting. However, the benefits of additional information must be balanced against the risk of low completion rates of unduly long surveys.

The survey provides valuable data to help inform future research into the efficacy of interventions for the upper limb in infants with perinatal stroke. It suggests that monthly review is a realistic aspiration in the context of a clinical trial. Furthermore, therapists do not focus on the function of the potentially affected side in infants but rather adopt a bilateral approach. This forms a fundamental difference between current care and the approach proposed in our parent-delivered intervention. Finally, the use of assessments such as GM, AHA, mini-AHA, and HAI is rare; considerable investment in therapist training in undertaking the assessments will be required.

In conclusion, therapy service provision after perinatal stroke varies within UK; this is not unexpected in the absence of clinical guidelines and a robust evidence base for intervention, as well as variability in caseload and other demands on time among individual practitioners. It remains essential to provide early referral to therapy services, clinical follow-up by appropriately trained staff using validated assessments, early identification and management of motor and other impairments, and parental support.

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